ENGAGE 2019
INELEGANCE
AND WHY WE MIGHT DESIRE IT
WORKSHOP REPORT
BentleyCrudgington
In founding Gay Men’s Health Crisis (GMHC) and the AIDS Coalition To Unleash Power (ACT-UP), Larry Kramer created two of the earliest centrally organised examples of health research engagement and public and patient involvement. These activists were not rejecting the research itself but denouncing its “elegant” nature.

What would inelegant engagement look like and why might we desire it? What would it look like if we acted up and queered engagement, lavishing our time, skills, creativity and resources on the public and not researchers? This participatory workshop will explore these possibilities to produce an inelegant manifesto of change.
As an introduction to the concept of inelegance, and why we might desire it, we considered some of the inventions used by ACT UP and compared them with two current areas of social theory. We borrowed from queer theory and visual culture analysis to consider how we, as engagement professionals, frame our invitations, construct our publics and operate within institutional structures.

We used these experiences to identify what systems need to be in place and which barriers need managing to allow us to become inelegant.

We reviewed these ideas together and clustered them into emerging themes. We then named each cluster with an action to create an inelegant manifesto.

This report summarises what we learnt together.
In January 1982, Larry Kramer, a New York based writer, held a gathering of around eighty gay men at his apartment to discuss the emerging reports of a “gay cancer”. This lead to the formation of the Gay Men’s Health Crisis (GMHC) – a non-profit community based organisation with the aim to “end the AIDS epidemic and uplift the lives of all affected (1).

In 1983, Kramer resigned from the board of GMHC, believing it to be “politically impotent”. Kramer went on to help form AIDS Coalition To Unleash Power (ACT UP) (1).

This workshop was held a few days from the 30th anniversary of ACT UP’s Stop the Church protest on December 10th 1989, St Patrick’s Cathedral, New York, which remains one of their most public and memorable interventions. However, there were many others.
To celebrate the *New York Times* buying its first fax machine, ACT UP faxed them a mile of black paper to protest their silence on the AIDS crisis. The previous page has not been left blank but intentionally *black* to honour this inelegant method of controlling the narrative.

These protest were not about rejecting medical science. They were, however, denouncing the “elegant” framing of scientific research (2).

They were rejecting the idea that what is wanted or needed is defined by the institute and not the consumer or the citizen. They sought to challenge the validity of where people are seen to derive authority from.

Public Engagement emerged from mandates to better communicate the benefits of publicly funded scientific research. It has evolved and diversified from this single purpose, but, it is worth considering what the practice of engagement inherited from its ancestral form, and if activism offers a robust framework with which to critique our practice and instigate change.
The visual essay “You Need to Calm Down”(3), by prominent social commentator, Taylor Swift, is widely heralded piece of queer inclusivity.

The essay opens with Swift, a white, straight, cis heterosexual female, in Agent Provocateur robe and customised eye mask (available on her merchandise store) asking the public to “calm down”.

Let us consider how Swift has constructed the public.
The visual signifiers used to describe the public are; buck teeth, poor hygiene, sunburn, stetsons, denim, misspelt signs with homophobic/biblical references.

This informs us the public are to be considered as poor, uneducated, and pitiful. They unworthy of interaction and are to be patronised and dismissed.

What are the consequences of constructing the public in a way that does not allow them to change?

Is there an inelegant way?
In other scene an aerial shot captures Taylor Swift, Bobby Berk, Todrick Hall, Jonathan Van Ness, Antoni Porowski and Karamo Brown, sitting at a table, behind a yellow picket fence, mid tea party.

Is this inclusivity or performative inclusion - when the research subject is treated like an object?

Each time individuals or groups appear in this essay they are in a box, on a stage, or behind a barrier. Guest have been preselected to be displayed. The spaces they occupy have been built to order. To be included is to be assimilated.

You are included not because you have value but because you are of value to the Taylor-Industrial-Complex.

It would appear, except for possible hypothetical footprints on her gown, Taylor Swift remains unwaveringly elegant.
If we now consider our second visual essay, Ever Again by Robyn (4).

This also centres around a solo, white, cis, het, white female in couture (Louis Vuitton), with high production values and strong aesthetics.

Why then does this feel so much queerer and more inclusive and why might we care?

Is there inelegance we can learn from?
What can be learnt from the way Robyn constructs public?

In this essay, the public is absent. This does not feel a problem, because, here, the public have not been predefined and allocated spaces to occur in and roles to play. Here, the classic structures and indicators of privilege and elitism have been dismantled; there has been significant unbuilding.

This is a rejection of elegance and therefore inherently queer and more inclusive.

Can inelegance be more than an aesthetic? If we were to adopt it as a strategy, what would that look like?
Since the public are visually absent from this work a discourse analysis may help reveal the intent of artist.

“How 'bout we stop arguing and do something else?
So many things we haven't tried
Baby, you know we're just getting started
Daddy issues and silly games
That shit got so lame
That shit got so lame”

(4)

It is impossible to say if these lyrics are from an auto-ethnography identifying a desire to remain cautiously and optimistically venerable or a succinct critique of the current discourse about public engagement in UK institutions.
Dr Iris Long was a retired chemist who, around, March 1987, attended an ACT-UP meeting. She went on to play a vital role in the movement; forming the Treatment and Data Committee and organising the AIDS Treatment Registry (5).

However, her greatest gift may not have been the ability to only explain the products of scientific research but also the institutional and legislative structures in which it operated.

In revealing how science was constructed and conducted and not just what science produced, Iris helped ACT UP target and unmake the boundaries between the community and researcher, to move from passive consumers to active consultants.
Workshop participants were asked to consider what an inelegant approach might look like and how it may help us in transforming engagement.

Or, in short, how to be more Iris?

Collectively it was proposed that an inelegant approach could help us transform engagement by:

- Re-thinking funding approaches
- Widening the register by disruptive methods
- Change people & places (to increase diversity)
- Giving power to the people
- Challenge power structures, hierarchies and policy.
- Maintain your inelegant principles

Below are the ideas and suggestions, collected in the workshop, of these actions might be achieved.
Re-think funding approach

- give community researchers the budget to spend
- public decision making on PE funding panels
- don’t have separate research + PPI budgets – make them the same
- understand the funding structure
- do we/they need money?
- hand over funding and control of funding
- philanthropic seed funding to community addressing issues our researchers are interested in
Widening the register by disruptive methods

- use responsive, equitable, ethical methods
- get all types of researchers in one room together, e.g. genetics, clinical, pathology
- community editing/writing/translating Wikipedia
- create entire project in one day
- research findings available to all, easy language
- silent projects; no words, no language
- patients non research collaboration
- exhibition curated by the public
Change people & places (to increase diversity)

- do it (not IT) in an unexpected place
- research a non-core audience
- move to the community
- identify “community hubs” and how to access them (not necessarily community leaders)
- libraries as research hubs for everyone
Giving power to the people

- accept the usefulness of the ‘public’
- everyone should be able to opt into research
- change who participates
- co-production of evaluative process
- power to the people
- community based engagement
- ask community to develop all you communication with their formats and platforms (with funding from you)
- a citizen jury
- upskilling neighbours as community researchers
- the people write the strategy
Challenge power structures, hierarchies and policy.

- research still has worth without application
- break down the hierarchy in academia
- no evaluation forms
- fund research on actual population (not just white healthy men)
- **really** challenge stereotypes
- ‘impact’ can still be valuable even if it’s not REF-able
- rate the research (how useful is it to you)
- break the rules
Maintain your inelegant principles

- have fun
- be unapologetically messy
- be risky
- moving from the binary to an ecology
CONCLUSION

It is important to practice critical reflection and in doing so ask the question how inelegant is this manifesto?

Have engagement practitioners become institutionalised and therefore struggle to imagine a radically different future outside the current reality?

Is this because there are too few opportunities to think creatively and optimistically? Or, perhaps, precarity, erasure/invisibility and constant undervaluing demands we spend all our time and energy simply fighting to exist and there is little left to image a better future, let alone realise it?

In the opening scenes of her Netflix documentary Miss Americana (6), Swift states “my entire moral code is the need to be perceived as good”. Not to be good or do good but to be perceived as good.

Is the aim of engagement to do good or to be perceived as doing good? Have the current impact and REF agendas reduced engagement to cultivating perceptions of worth rather than collaboratively sharing value?

Can inelegance offer not on a model for rejecting the status quo but also to imagine a better future for engagement?
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CONTACT

Bentley Crudgington is a creative facilitator based in Manchester. They have interests in queer things, monstrous things, low theory and, above all, inelegance.

If you have any questions, comments or confessions, you can reach them at bentley.crudgington@manchester.ac.uk or @incidentallyb on twitter.
REFERENCES


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